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REVIEW

Repercussions on the family from the birth and care of children with multiple disabilities: a qualitative meta-synthesis

Repercussões do nascimento e do cuidado de crianças com deficiência múltipla na família: uma metassíntese qualitativa

Repercusiones del nacimiento y del cuidado de niños con discapacidad múltiple en la familia: una metasíntesis cualitativa

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Abstract

Multiple disabilities in children, present in various syndromes, involve physical, economic, and social problems and affect the parents of these children and their families. The attempt to learn more about this problem from a qualitative perspective gave rise to the current study's objective, namely to identify and summarize the scientific literature on the repercussions on the family from the birth and care of a child with multiple disabilities. This is a qualitative meta-synthesis of data from Scopus, PsycInfo, and SciELO, using the following descriptors: qualitative; children with disabilities; parent-child relations; family relations; and caregivers. The data were analyzed in three stages according to the method proposed by Noblit & Hare: extraction of first-order concepts; production of second-order concepts; and interpretative synthesis. After the search and eligibility process, eight studies were included, from which emerged six second-order concepts: social restriction; strain on family relations; feelings of affliction; financial instability; changes in the family dynamics; and stress to health and wellbeing. Three syntheses were developed, based on these concepts: disability and ideal parenthood; burden of care; and family redefinitions and adaptations. The studies showed that parents and families experience difficulties resulting from social representations of multiple disabilities and the burden of care (health problems, limitations to other activities, increased financial costs, and changes in the family's routine). They also indicate that these elements invade and can interfere in family and social relations.

Qualitative Analysis; Disabled Children; Parent-Child Relations; Family Relations; Caregivers

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Introduction

In Brazil, in 2015 and 2016, especially in the Northeast region, there was a significant increase in the number of children born with microcephaly and/or other alterations of the central nervous system (CNS) associated with congenital infections. In November 2015, the Ministry of Health confirmed the association between the microcephaly outbreak and the Zika virus epidemic, backed by national epidemiological surveillance data and the identification of viral RNA in samples of cerebral spinal fluid from newborns. By May 2018, more than 3,000 cases had already been confirmed according to the latest Ministry of Health epidemiological bulletin [1].

Since then, many clinical and epidemiological studies have been published on microcephaly and the alterations in growth and development related to Zika virus infection, but the literature contains little on the social and emotional impact and the financial burden for families and the preparation of health teams to address the challenge of caring for the children and their families over time [2]. To mitigate this gap, we conducted a literature review of diseases in which the disabilities (mental/visual/hearing/physical) are similar to those caused by microcephaly and that dealt with the family repercussions of caring for children with such disabilities. We thus found the concept of multiple disabilities quite appropriate for this undertaking.

Brazil's National Policy for Special Education (PNEE) defines multiple disability as the association, in the same individual, of two or more primary disabilities involving delays in overall development and adaptive capacity [3]. The impact of multiple disabilities is highly variable and depends on various factors such as the types and amounts of associated primary disabilities, the breadth or extent of affected aspects, age at onset of the disabilities, environmental and family factors, and the efficiency of educational and health interventions, among others [4].

According to Brunoni et al. [2], daily living with a child with a chronic condition such as those affecting children with multiple disabilities alters the family's functioning and directly impacts the caregivers' living conditions. The authors add that the burden of care tends to fall heavily on the mother. Marcon et al. [5] explain that maternal care for a child with a chronic condition is an exhaustive task that produces overload, due to the countless needs resulting from the child's condition. However, this overload is not related only to the demands of care, but to the mother's constant feelings, such as concern for the child's survival and the guilt, helplessness, and ignorance of how to care for the child. Such difficulties also permeate the family as a whole and require the production of knowledge concerning the constitutive elements of this problem.

Castro & Piccinini [6], in a review study, concluded that family relations are essential for coping adequately with chronic illnesses and the prolonged treatment that is usually necessary for such conditions. Family follow-up to verify mental health indicators, social support, and quality of life is thus essential to care for children with developmental disorders, especially when associated with intellectual impairment [2].

In a qualitative study on the views of parents and teachers concerning school inclusion of children with multiple disabilities, the parents report their feelings when learning of the diagnosis (shock, sadness, anguish, alarm, fear, insecurity) and difficulties in understanding it, since it causes changes in social participation in the workplace, religious life, and leisure time [7]. According to Santos [8], the main challenges for understanding the disability as a restriction on social participation consists of grasping the environmental barriers and factors that allow viewing it as an issue in the scope of promotion of justice and social equality, and not only in the field of clinical medicine and treatment.

Elucidating the repercussions on parents and other family members from the birth and care of children with multiple disabilities can produce useful information for health professionals and administrators to conceive preventive strategies for the caregiver's health, for actions and policies to support the family, and to help focus the attention of health professionals on aspects that transcend clinical treatment of the disability. This can help promote comprehensive care for the child and family, assuming collaborative and inter-sector action.

The aim of this study was thus to identify and summarize reports from the scientific literature concerning the repercussions on the family from the birth and care of children with multiple disabilities.

Methodological aspects

This is a qualitative meta-synthesis whose purpose is to create expanded interpretative translations of all the studies examined in a given domain, in order for the result to be faithful to the interpretative translation of each particular study. This means the researcher's interpretation – the synthesis – of the primary data's results (original qualitative studies) [9].

Meta-syntheses offer a coherent description or explanation of a given event or experience. Their validity is not in a logical replication, but in an integrative logic whose conclusions are accommodated in a creative and coherent process exhibited in the final product [10].

Search process and inclusion criteria

A systematic search was performed from September to October 2017 in the SciELO (https://www.scielo.org/), Scopus (https://www.scopus.com) and PsyInfo (https://www.apa.org/pubs/databases/psycinfo/) databases, using the following descriptors from the *Medical Subject Headings* (MeSH; https://www.ncbi.nlm.nih.gov/mesh) and their correlates in Portuguese and English: (*parent-child relationships* OR *parent-child relations* OR *relations, parent-child* OR *family relations* OR *family dynamics* OR *family relationships*) OR (*caregiver* OR *caregiver, family* OR *caregiver, spouse* OR *caregivers*) AND (*children with disability* OR *handicapped children* OR *disabled child* OR *children with disabilities*) AND (*narrative analysis* OR *content analysis* OR *discourse analysis* OR *semi-structured interviews* OR *interviews* OR *qualitative method* OR *qualitative study*).

The search selected qualitative studies with full texts published in peer-reviewed journals from 2013 to 2017 that addressed the repercussions on the family from the birth of a child with multiple disabilities or from the child's care.

An initial reading of the titles and abstracts was performed to select potentially relevant articles for the research question. A second reading was then performed, this time of the full texts of the pre-selected articles, considering the sample's inclusion and exclusion criteria. In case of doubt, another evaluator read the article to reach a decision on inclusion. Figure 1 shows the search, eligibility, and inclusion process.

All the selected articles were submitted to the quality assessment model *Critical Appraisal Skills Programme* (CASP) [11]. Quality articles in CASP were studies that covered the highest number of items belonging to each of the ten themes in this assessment (i.e.: objectives, method, selection of participants, study design, data collection, researcher-participant relationship, ethical objectives of the research, data analysis, presentation of the results, and study validity), as shown in Box 1.

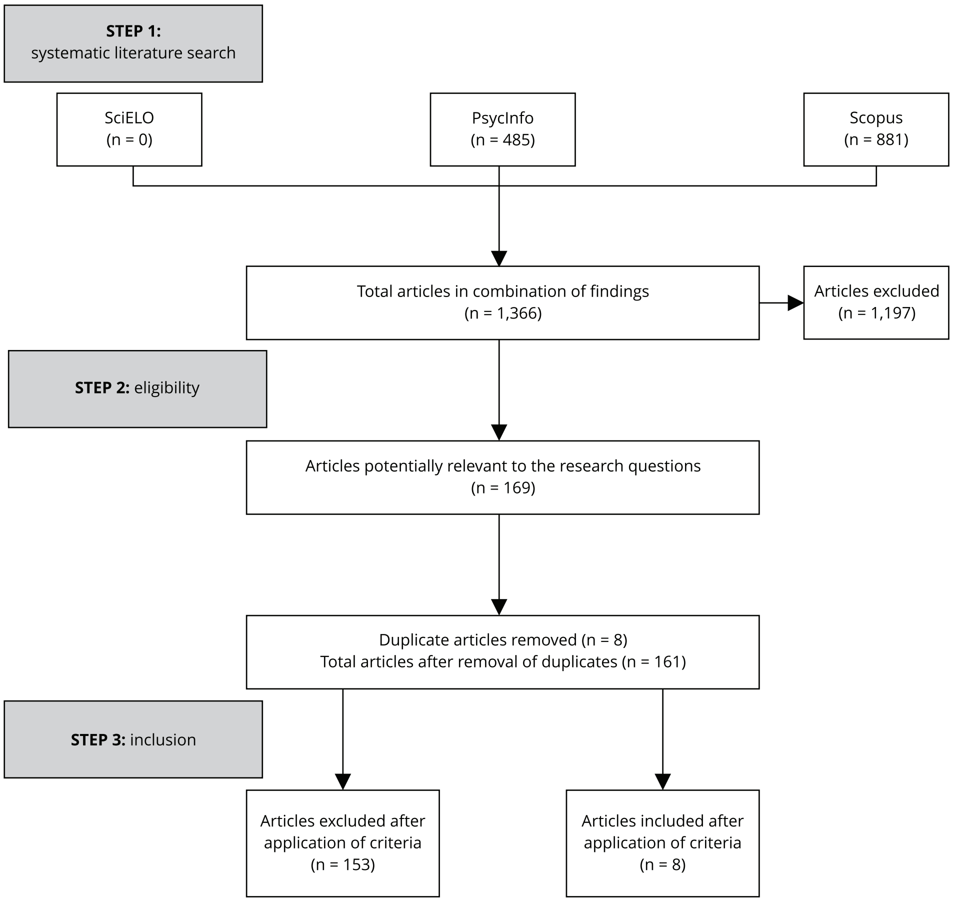
Data analysis

The literature describes three strategies to summarize the results of qualitative studies. The first involves the integration of results from multiple paths developed in a research program by a single researcher. The second consists of the synthesis of research results from different researchers, integrated by techniques such as comparative qualitative analysis, reciprocal translation of key metaphors (categorizing the information obtained from individual data in "key variables"), and content analysis, among others. The third strategy involves the use of quantitative methods to combine qualitative results from different studies in order to transform them into data that can be analyzed statistically (meta-summarization) [9,10,12,13]. The current review adopted the second strategy, since the target studies present many similarities, so it is thus recommended to measure them by the constantly scrutinizing and comparing the ideas and concepts contained in the original studies [14].

As proposed by Noblit & Hare [14] for meta-syntheses, the review's data were organized and analyzed in three stages. In the first, we identified the first-order concepts contained in the original articles' main findings, extracted according to their pertinence for answering the study's questions. The second stage was the interpretative process, comparing and grouping the first-order concepts extracted from at least two original studies, pulling up the second-order concepts, and the third stage led to the synthesis, consisting of reinterpreting the second-order concepts based on theories that help explain the findings.

Figure 1

Flowchart of the article search, eligibility, and inclusion.



Results

After merging the results from the databases, we read the titles and abstracts and removed the duplicates, resulting in 161 articles. Eight articles were selected according to the inclusion and exclusion criteria. Box 2 shows the main characteristics and first-order concepts identified in the articles.

Based on the research questions, the second order of data analysis generated the following six second-order concepts:

(1) Social restriction

Social restriction was expressed in the articles as the attempt by parents to protect themselves and their children from social embarrassment and humiliation, due to the stigma and prejudice resulting from standards of social acceptance that are frequently set by persons without disabilities [15,16,17,18]. However, the level of Social restriction depends on how the behavior, understanding, and beliefs of others towards the disability affect the parents' initiative in their socialization and that of their children [15,17,18].

Box 1

Quality analysis of studies according to the *Critical Appraisal Skills Programme* (CASP) [11].

	Paget et al. [20]	**Williams & Murray [18]**	**Park & Chung [19]**	**Dehghan et al. [16]**	**Jordan & Linden [15]**	**Faw & Leustek [17]**	**Mas et al. [21]**	**Kvarme et al. [22]**
1) Was there a clear statement of the aims of the research?								
a. What was the goal of the research?	X	X	X	X	X	X	X	X
b. Why it was important?	X	X	X	X	X	X	X	X
c. Is it relevant?	X	X	X	X	X	X	X	X
2) Is a qualitative methodoloy appropriate?								
a. The research seeks to interpret or illuminate the actions and/or subjetive experiences of research participants?	X	X	X	X	X	X	X	X
3) Was the research design appropriate to address the aims of the research?								
a. Did the researcher justify the research design (e.g. did he discuss how he decided which method to use)?	X	X	X	X	X	X	X	X
4) Was the recruitment strategy appropriate to the aims of the research?								
a. Did the researcher explain how the participants were selected?	X	X	X	X	X	X	X	X
b. Did they explain why the participants they selected were the most appropriate to provide access to the tyoe of knowledge sought by the study?		X	X		X	X	X	
c. Is there some discussion on recruitment (e.g. why some people chose not to take part)?		X					X	X
5) Was the data collected in a way that addressed the research issue?								
a. Was the data collection scenario justified?	X	X	X		X	X		X
b. Is it clear how the data were collected (e.g. focus group, semi-structured interview...)?	X	X	X	X	X	X	X	X
c. Did the researchers justify the choice of methods?		X					X	X
d. Did the researchers made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)?	X	X				X	X	X
e. Were the methods modified during the study? If yes, did the researchers explain how and why?								
f. Is the data format clear (e.g.: tape recordings, video material, notes etc.)?	X	X	X	X	X	X	X	X
g. Did the researchers discuss the data saturation?	X	X	X			X	X	X

(continues)

Box 1 (continued)

	Paget et al.[20]	Williams & Murray[18]	Park & Chung[19]	Dehghan et al.[16]	Jordan & Linden[15]	Faw & Leustek[17]	Mas et al.[21]	Kvarme et al.[22]
6) Has the relationship between researcher and participants been adequately considered?								
a. Did the researchers criticalyy examine their own role, bias, and influence during formulation of the study questions, data collection, sample selection, and choice of site?			X					
b. Did the researchers answer how they address the implications of any changes to the reseach project or the occurrence of unexpected events during the study?		X		X				
7) Have ethical isses been taken into consideration?								
a. Are there sufficient data on how the research was explained to participants in relation to maintenance of ethical standards?							X	
b. Did the researchers discuss the questions raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)?	X	X		X	X			X
c. Is there approval by the ethics committee?	X	X	X	X	X	X	X	X
8) Was the data analysis sufficiently rigorous?								
a. Is there an in-depth description of the analysis process?	X	X	X	X	X	X	X	X
b. Is it clear how categories/themes were derived from the data, in case of use of thematic analysis?	X	X	X	X	X	X	X	X
c. Did the researchers explain how the data presented were selected from the original sample to demonstrate the analysis process?	X	X	X	X	X	X	X	X
d. Were the data presented sufficiently to support the findings?	X	X	X	X	X	X	X	X
e. Was the extent of the data's contradictions addressed?	X				X			
f. Did the researcher critically examine his own role, potential bias, and influence during the data analysis and selection?								
9) Is there a clear statement of findings?								
a. Are the findings explicit?	X	X	X	X	X	X	X	X
b. Is there an adequate discussion of the evidence for and against the researchers' arguments?	X	X	X	X	X	X	X	X
c. Did the researchers discuss the findings' credibility (e.g. triangulation, respondent validation, more than one analyst)?		X	X				X	
d. Were the findings discussed in light of the original research question?	X	X	X	X	X	X	X	X

(continues)

Box 1 (continued)

	Paget et al. [20]	Williams & Murray [18]	Park & Chung [19]	Dehghan et al. [16]	Jordan & Linden [15]	Faw & Leustek [17]	Mas et al. [21]	Kvarme et al. [22]
10) How valuable is the research?								
a. Do the researchers discuss the study's contribution to the existing knowledge and understanding (e.g. do they address the findings in relation to current practice and policy or the relevant literature)?	X	X	X	X	X	X	X	X
b. Do the researchers identify new areas in which research is needed?		X	X	X		X		X
c. Did the researchers discuss whether and how the data can be transferred to another population, considering that other research forms may be used?	X	X	X		X			

Box 2

Description of the selected articles and first-order concepts.

Author (country)	Objective	Methodology	First-order concepts
Paget et al. [20] (United Kingdom)	Explore the perspectives and experiences of caregivers of children with disabilities.	Exploratory study with thematic analysis of in-depth semi-structured interviews with 14 parents.	Physical overload; Limitation on household chores; Limitation on social activities; Lack of time to care for other children; Increased financial costs (transportation, medicines, appointments).
Williams & Murray [18] (Australia)	Understand how mothers that care for children with disabilities negotiate the social exclusion they experience.	Phenomenological study with interpretative phenomenological analysis based on in-depth interviews with 13 mothers.	Social exclusion; Anxiety and stress over what they should do, what they would like to do, and their capacity to do it; Lack of time and opportunity for study, work, and leisure; Financial restrictions (additional costs of a child with disability); Pressure and guilt associated with expectations of motherhood.
Park & Chung [19] (South Korea)	Explore the cultural understandings on parenthood in the context of childhood disability and what factors contribute to adaptation.	Exploratory study with content analysis of reports by 18 mothers through focus group.	Social isolation; Feeling of mourning, despair, disappointment, and failure in relation to the diagnosis; Physical overload of care associated with aches and pains; Need to quit work; Change in routine due to medical treatments and services; Less contact with the other children; Lack of time for oneself; Denial of the child by the family.
Dehghan et al. [16] (Iran)	Explore the experiences of mothers of children with cerebral palsy in the community.	Exploratory study with content analysis of in-depth semi-structured interviews with 14 mothers.	Challenges for social participation due to anxiety, fear, and the child's dependence; Financial difficulties to cover expenses with the child's rehabilitation and mother's health; Lack of time for oneself; Marital problems (separation); Stigma from other family members.

(continues)

Box 2 (continued)

Artigo (país)	Objetivo	Metodologia	Conceitos de primeira ordem
Jordan & Linden [15] (United Kingdom)	Explore the perspectives and experiences of caregivers of children with disability.	Exploratory study with thematic analysis of in-depth semi-structured interviews with 14 parents.	Social withdrawal in the attempt to protect against social prejudice; Fear and anxiety concerning the children's future; Guilt associated with the powerlessness to relieve the child's pain or fear of inflicting suffering on the child; Frustration due to the child being "different" from other children; Physical and mental exhaustion from the repetitiveness of care; Lack of time for oneself; Restrictions on capacity to work; Financial insecurity; "Struggle" for support services; Feeling of loss of oneself and of the projected ideal child.
Faw & Leustek [17] (United States)	Identify the challenges parents face with their informal support networks.	Exploratory study via in-depth interviews with 40 pairs of parents with network members. Data analysis used the open and axial method (Strauss & Corbin, 1990).	Social isolation; Complications in relations with spouse and other children; Change of routine and behavior due to stigma and logistic challenges; Problems in establishing roles as parents-caregivers and negotiating responsibilities with others; Quitting work to care for the children; Fears and sadness over the child's future socialization and prospects.
Mas et al. [21] (Spain)	Understand how families adapt their routines to raising a child with intellectual or developmental disability.	Exploratory study using semi-structured interviews plus a questionnaire with 18 families. Qualitative analysis of transcriptions used EthnoNotes software (Lieber et al. 2003).	Reduction in workweek, changes in shifts, and work absences; Importance of work for mental health (autonomy and personal satisfaction); Denial of disability by parents and family; Problems in family relations with other children and spouse.
Kvarme et al. [22] (Norway)	Understand how parents of children with complex needs manage family life and the repercussions on their health and quality of life.	Exploratory study with thematic analysis of in-depth interviews and focus group with 18 mothers and 9 fathers.	Lack of sufficient time to care for the healthy children; Difficulties in marital relations (divorce); Social stigma and constraints on leisure time; Increased workweek to improve family's financial situation; Impossibility of studying and/or working away from home; Health problems due to overload from care.

Source: primary data.

Another factor involved in social restriction is the overload from care for children with multiple disabilities. The impairments require more care, supervision, and thus more time from caregivers. To adapt to the child's needs, they often need to abandon some activities (both work and leisure-time) that would otherwise favor social interaction [15,16,18,19,20].

Lack of community and/or family support also appeared as a difficulty in the social lives of caregivers of children with multiple disabilities. This appears in the articles when mothers report that they feel they lack time for social participation, because they are always occupied caring for the child with disability. Mothers that receive support from their husbands, relatives, neighbors, or friends can participate more easily [16,17].

Insecurity towards the child's behavior and the parents' feelings and emotions about the children also appear as challenges for social participation [15,16,17]. Many parents experience an inner conflict when spending any time away from the child. These caregivers are often racked by guilt, anxiety, and insecurity when leaving the child in the care of others to engage in social activities. Besides, to avoid calling attention and causing embarrassment, they do without attending some social events, due to the possibility of some unexpected behavior by the child.

(2) Financial instability

The studies showed that parents of children with multiple disabilities suffer from financial instability due to the additional costs of caring for the child and the need to make adaptations or abandon their work activities. Expenses with the child's rehabilitation and health involve transportation, medicines, and appointments that often exceed the family income [16,18,20].

Lack of financial support from the family or government and shortage of public services to guarantee adequate care for these children are other complicating factors for the family's financial stability, since the parents are forced to pay for the services their children need [21]. In some cases one parent, usually the father, works fulltime, puts in overtime, or adds another informal paid activity in the attempt to improve the family's financial situation [22]. On parent, usually the mother, often has to quit work, which appears in the studies as an aggravating factor or cause of financial difficulties [15,17,19,21].

(3) Strain on family relations

Caring for children with multiple disabilities also involves difficulties in family relations, both in the nuclear and expanded family. Studies indicate that parents experience marital problems because of the inability to devote time to the relationship, due to the burden of care, or because they have to work more to support the family. Sharing responsibilities in the child's care also appeared as a factor in marital conflicts, weakening the relationship [17,19,22]. The father's shame, feeling of failure, and insecurity in relation to the birth of a child with disability were identified in the articles as causes of the couples' separation [16,22]. Rejection by other family members due to the stigma involved in the disability causes friction and alienation between the child's parents and the siblings, mother, father, uncles, aunts, etc. [16,19].

Another difficulty was the change in the relationship with the other children, also associated with the parents' lack of time due to the need for greater attention to the more vulnerable child. Parents expressed deep regret that they were unable to participate more effectively in their other children's lives [17,19,22]. For those who counted on support from the spouse, sharing tasks to allow paying the necessary attention to the other children was a coping strategy that mitigated this difficulty.

(4) Feelings of affliction

When parents receive the diagnosis of a child with multiple disabilities, they begin to deal with a feeling of failure and personal frustration related to the loss of the ideal child they have projected. This is because the diagnosis of a disability represents a break with the parents' plans and expectations concerning the child's education, along with denial, sadness, disappointment, despair, and in the long run, self-censorship and tallying losses in broader career opportunities and social and family life. Acceptance of the new reality and a focus on meeting the child's needs help parents dispel these feelings [15,19]. Parents further report that the belief in their children's improvement or cure (reinforced by omission of information by some professionals) leads to later disappointment and further aggravates their feeling of frustration [19]. The awareness that their children will probably never experience key milestones like living alone, working, marrying, and having children was also manifested in the studies as a reason for parents' frustration [17].

Another feeling that afflicts parents is guilt, appearing as perspectives in the studies. The first comes having conceived a "different" and "handicapped" child, thus perceived as inferior to other children. The second is the feeling of powerlessness to relieve the child's suffering, even in acts inherent to the care such as submitting him or her to painful procedures [15]. Finally, the feeling of guilt also appears in response to non-compliance with society's expectations concerning the role of Mother and Father according to standards of normality. The social image of the "perfect mother" and "unconditional love" that involves motherhood and dictates what it means to be a "good mother" is an even more stressful challenge for mothers of children with multiple disabilities [18].

Fear and anxiety are also nagging feelings for parents of children with multiple disabilities and are caused by the perception of vulnerability and the need to protect their children. Besides, knowing that they themselves may die first leaves parents fearful for their children's survival and wellbeing [15,17].

(5) Change in the family dynamics

Studies also identified changes in family dynamics as repercussions from the care of a child with multiple disabilities. Logistic challenges from the need to manage outside help, economic resources, and complex medical schedules require adaptations to the family routine [17,19]. For some parents, the complexity of such adaptations comes with difficulty in defining their roles as parents/caregivers and negotiating responsibilities with other family members. The parents' change of routine and behavior also emerged as a defense mechanism to avoid embarrassing situations from the social stigma [17].

(6) Stress to health and wellbeing

The physical and mental exhaustion from the overload of care for a child with multiple disabilities was the main consequence detected in the stress for the caregiver's health and wellbeing [15,20]. Musculoskeletal disorders, disabling pain, chronic fatigue, sleep disorders, and mental health problems were associated with the repetitiveness and burden of the care for the child, as reported by mothers and fathers in various articles [19,22]. An aggravating factor for the principal caregiver's health and wellbeing was the need to "struggle" to ensure access to support services for the child [15].

The fulltime care required by a child with multiple disabilities means that the principal caregivers give up their leisure-time and self-care activities. "Lack of time for myself" was cited as a difficulty by parents and other family members in the studies [15,16,19,22], directly affecting their self-esteem and mental health.

Discussion

The second-order concepts described in the previous section led us to two concepts that oriented the subsequent synthesis. The first is family resilience, defined as the dynamic process based on the system of family beliefs, organizational patterns, and communication involving the strengths and resources that families develop in stressful circumstances [23]. The second concept is that of social representations, as proposed by Moscovici [24], or the set of perceptions, feelings, norms, and values in individual and collective experiences that intervene in the definition of social identity and that materialize in the practices permeating attitudes and worldviews.

It was thus possible to build a synthesis with three themes: disability and ideal parenthood; burden of care for parents of a child with disability; and family redefinitions and adaptations.

Disability and ideal parenthood

The studies showed that the repercussions on the family from a child with multiple disabilities come from the inherent difficulties with the child's condition, but they also relate to the way the child's disability shakes the parents' beliefs concerning parenthood, a term used in the French psychoanalytic literature since the 1960s, to mark the mark the process and construct dimensions in the exercise of the relationship between the parents and the child before and after birth [25].

The concepts extracted from the articles revealed that in a society in which differences are viewed as "flaws" or "handicaps", the sense of parenthood is permeated by the demand to produce and develop healthy, cooperative, and efficient individuals. According to prevailing capitalist logic, a body that fails to produce profit is considered invalid [26]. Fathering or mothering a child with disability thus becomes a dehumanizing experience, to the extent that it strips these men and women of the condition of equality with others, marking them as inferior [27].

In the attempt to meet these demands that involve the role of the ideal father and mother, parents idealize the "perfect child" and tend to show their best through the child, seeking recognition for their success and self-affirmation of their parental role [28]. When planning a child, no couple expects or organizes to have a child outside of what are considered normal standards. They project an independent and productive child, and from conception on they fantasize about the baby's sex and future scholastic performance, career, and sexual orientation [29]. This expectation towards one's offspring is part of human nature, but the current study's results lead us to conclude that the birth of a child with multiple disabilities puts a check on this expectation and the parents' beliefs acquired throughout life, which can affect their relations with the child and thus the entire process of his or her acceptance.

Pinker [30] noted that parents' beliefs are implicit in the decisions they make and orient the way they raise their children and their parental values and goals. Biasoli-Alves [31] found that the parents' shared values and beliefs concerning the child's development influence their parenting behaviors and practices, besides affecting their interaction with the children.

In attempting to understand parental relations in families with children with atypical development, Sá & Rabinovich [28] also concluded that each family member's experiences and beliefs help determine how the disability is viewed, and the more a disability in a family has a negative connotation, the more complex the parents' relations are with the child. A study by Pinquart [32] aimed to compare the quality of the relationship between parents and children, as well as the parental behaviors and styles between families of children with normal development and families of children with chronic physical illness. The researcher found that the relationship between parents and children tended to be less positive in families that had a child with a chronic physical illness, which corroborates the interpretation of our study's results.

The results of this meta-synthesis also lead us to conclude that when parental values are consistent with the hegemonic sociocultural constructs on disability, i.e., rooted in stigma, etc., the parenting relations are pervaded by feelings of personal frustration, guilt, disappointment, and failure. These feelings are linked to mourning over the loss of the idealized perfect child and the impossibility of meeting social expectations concerning fatherhood and motherhood. The articles analyzed here showed that in a historical context in which the woman's role is defined biologically and characterized primarily by motherhood, the simple fact of having born a child that falls outside of so-called normal standards in society suffices to spawn distortions of self-recrimination, manifested in the above-mentioned feelings [33].

Various authors have identified this relationship when studying repercussions on parents' lives from the birth of a child with disability. Shock, anxiety, sadness, guilt, uncertainties, insecurity, denial, stress, and increased difficulty in adjusting, besides depression, are frequently associated with mourning over the loss of the idealized child, according to the parents' reports [32,34,35,36,37,38,39,40,41,42,43,44,45].

In keeping with our findings, Buscaglia [46] points to the relationship between social stigma towards disability and the distress of mothers/caregivers, confirming that ignorant and prejudiced attitudes cause incalculable suffering for children with disabilities and their families. The horror and embarrassment of being stared at, ridiculed, or discriminated against were described repeatedly, and these attitudes towards the child (who is considered abnormal) affect the families directly and significantly. Corroborating this, Krinski [47] explains how the social view of disability affects mothers of children with multiple disabilities and states that the child's depreciation is felt by the mother as depreciation of herself, and that every condemnation of the child is a death sentence for her.

Finally, this analysis also found that the influence of sociocultural constructs of disability on the parents' beliefs and behaviors pushes them into social isolation in an attempt at protection from prejudice. Green [48], in a qualitative study of mothers of children with disability, found that the burden of care is related more to social rejection and stigma than to addressing issues of care and adaptation to the child's disability. This effect is worrisome, since the family's isolation means limitation of the social support networks. Coelho & Coelho [49] studied the psychosocial impact on parents of children with disability and found similar results to ours, concluding that these families, especially the parents, are pressured by immediate needs and social prejudices, developing a tendency to withdraw (particularly the mother). This isolation progressively reduces their social network and the resources mobilized by it, in a negative cycle of burgeoning needs and dwindling resources, meanwhile reducing the parents' social roles, now centered almost exclusively on their child.

Social representations of the child with multiple disabilities are not manifested only towards the child, but also towards parents and families, affecting the relations between children and their parents, mediated by the consequences of the ideally perfect child, while also impacting relations between parents and families and society at large through stigma and other forms of social prejudice. Such representations also produce practices (social isolation, reinforcement of the disadvantage produced by the disability, and others) that act as barriers to be faced in order not to undermine parental relations and for the support networks to remain strong and operational for the comprehensive care of the child and family.

Burden of care

Various studies have been published on the meanings and impacts of care for children with disability on their caregivers' lives [28,38,50,51,52,53,54]. In keeping with the findings described in the second-order concepts, the literature also shows that the daily lives of caregivers of children with disability are fraught with family conflicts, exacerbation of health conditions, disorders, and hardships closely related to the conditions that determine whether they are allowed to exercise their autonomy and social and participation, causing suffering for these individuals [15,16,45,51,55,56].

The studies reviewed here indicate that the repercussions of care for the child with multiple disabilities (from the physical overload on the caregiver, joint pain, physical fatigue, sleep disorders, etc.) are not the greatest sources of suffering for parents and families in relation to the attributions of care, even though these physical changes have often been cited in other studies on the subject [19,22,54,56,57]. The greatest impact of care appears to come from the restrictions the caregiver experiences on meeting the child's needs. The studies showed that the demand for fulltime care for the child with multiple disabilities ultimately leads to loss of the caregiver's own identity, compromising their personal, professional, and leisure-time fulfillment and self-care [16,58,59,60,61,62].

In addition to the above, the financial difficulty due to quitting work and the additional health costs for the child with multiple disabilities, as in other studies [40,41,57,61], is reported in the articles as a burden of care, even for families who live in developed countries where social welfare is a practical reality [15,16,18,22]. In countries with a more vulnerable political and economic context like Brazil and other nations in the Southern Hemisphere, the financial difficulties for families of children with multiple disabilities can become even more worse and cause more suffering. According to Diniz et al. [63], the combination of a social structure scarcely sensitive to disability or to the inclusion of persons with disabilities and a situation of extreme inequality and limited appreciation of care as a principle of collective wellbeing means that many women have to leave the work market, making them more vulnerable and denying them of the right to use their own labor to obtain other medium- and long-term social benefits, such as social security and supplements to the family income.

Another factor identified in the articles as a negative repercussion of the need to devote fulltime attention to the child with multiple disabilities is the strain on family relations, with the spouse, and with the other children or even with members of the extended family. Consistent with our findings, other studies of families of children with disabilities also concluded that due to the overload of care, families may become disorganized, conflicting, and fragmented with the parents' separation or with the lack of care for the other children [27,64,65].

Social representations on the caregiver's role were also mentioned by some authors [58,66,67] as a burden of care to the extent that they also trigger feelings of guilt, frustration, and fear in these individuals, but this perspective did not appear in the articles analyzed in this study.

Representations of the family caregiver in Hedler et al. [67] are linked to the vocational/obligational imaginary, depicted as an altruistic form of dedication and giving, abdicating from other aspirations to fulfill this role, which often involves suffering. Reinforcing the same idea, Azevedo & Santos [58] analyzed the meanings of care for families that share the home care of persons with physical disabilities and found (in the words of the caregivers) a strong sense of guilt over the disability. This guilty feeling combines with the belief that one should not leave a person with disability to his or her own devices (the sense of duty and responsibility) and produces an approach to caring that appears as a settling of accounts, a call to expiation of guilt (understood as a sin), through ingrained feelings that are rediscovered and rebuilt from memory. In the same study, ambivalent feelings such as love/hate, joy/suffering, euphoria/depression, acceptance/rejection were also common in the caregivers' words and are justified by the counterpoint to the physical and emotional strain and the satisfaction of performing one's duty.

Silva et al. [61], in their study on the impact of care for a child with multiple disabilities, also found in the mothers' reports that care for the child is a mixture of suffering and resignation but especially devotion, compensated for by the neurological gains from the rehabilitation. They conclude that the families' dedication to the child required adaptation to a range of feelings that were expressed by ambivalent reactions in the form of sadness, joy, conflicts, and gratifications, which over time led to overcoming difficulties and establishing a bond of love between the mother and child.

There is a need to problematize, between parents and families, these representations and their consequences, in order for care for the child with multiple disabilities not to be seen as additional suffering rather than as a natural process of life, which as such has been conducted on the basis of other values that can be socially learned, such as solidarity and commitment to life.

Family redefinitions and adaptations

Considering that the families have the social responsibility on their shoulders for providing care and an adequate environment for the child, the articles point to a series of changes in the family's daily routine that characterize a process of adaptation developed according to the parents' capacity for resilience. According to Greeff & Aspeling [68], resilience is a set of processes which, in adverse situations, lead to results as good as (or even better than) predicted in such situations. Gradner & Harmon [69], studied family resilience through a phenomenological qualitative analysis and concluded that this capacity in parents was related to positive attitudes towards life, organization and confidence, recognition of their strengths and weaknesses, the existence of supportive partners, a strong sense of the meaning of life, and religious beliefs, factors we also found in the articles in this review.

We found through our analysis that parents see flexibilization of roles, sharing tasks, and division of responsibilities over care for the child as important negotiations for adjusting the family's routine. In keeping with this finding, a study by Walsh [23,70] of parents of children with developmental disabilities also found that joint negotiation by family members concerning the obligations involved in care, planning new possibilities, options, and resources to overcome adversities are crucial attitudes for the process of adaptation.

Another important process for the family to adapt to the diagnosis of a child with multiple disabilities was the redefinition of parenting that allowed parents to shift the focus from the frustration and mourning over the idealized perfect child to meeting the child's needs. In the articles analyzed here, this is manifested in the parents' dedication to the search for rehabilitation services and their own waiving of their personal projects to care for the child fulltime. Consistent with this finding, Chacon [44] also states that during the process of adaptation, the real-life family takes the place previously occupied psychologically by the idealized family in the parents' eyes. This change also proves important for each member of the family to play his or her role with sufficient flexibility to redefine values and relational patterns and cope with necessary adaptations for caring for the child.

Spirituality and belief in a higher being were also reported in this review's articles as factors that helped parents and families to find meaning in the reality they are facing and strength to cope with the new condition (disability) that appears as a stressor in the family's organization. The same is found in other studies [71,72], that identify religiousness as an effective coping strategy for the family to adapt to the child's disability, not only at the time of diagnosis but also during tasks in caring for this child for life.

Li-Tsang et al. [73] add that parents that adapt successfully to the presence of a child with a diagnosis of congenital disability have a stable family structure and are generally outgoing and confident, have open attitudes, are efficient measuring time, and are highly motivated to find a local social support network for their children, attempting to solve the problems realistically. These aspects were also found in the studies analyzed in the current review. Our analyses indicated that the support in these networks is extremely important for the family's adaptation and the caregiver's health, considering that they provide support for the needs in care for the child and allow the caregivers time to perform important activities in their own lives, other than those concerning care for the child, as discussed by other authors [23,74,75,76].

Finally, despite the problems in coping with a disability in the family, with time, reacting to the adversity, adapting, creating solutions, and striving to optimize their children's development also become repercussions of the care when this reality is faced with optimism, persistence, solidarity, creativity, and especially love.

Conclusion

The literature pointed to various changes in the personal and daily lives of parents related to the birth and care of children with multiple disabilities. Many such changes are associated with the shock this disability produces in beliefs and expectations of parents and society, as well as the overload from responsibilities with the care. This overload can have negative repercussions on the caregivers' health and limits their activities, while causing difficulties in family relations and social participation, ultimately leading to problems for the caregivers' personal identity and mental health. The birth and care of a child with disability also affect the parents' daily lives, since caring for a child with multiple disabilities requires reorganizing the family routine and alters the family dynamics.

The study further showed that the arrival of a child with disability in the family frustrates the expectations based on social representations of parenthood and produces feelings of failure, guilt, and sadness related to mourning over the loss of the idealized perfect child. The understanding and social behavior pertaining to the disability also alter the family's daily routine, to the extent that the caregivers take a defensive stance against the stigma in order to avoid social embarrassment. Such isolation affects the parents' personal lives and curtails their social support networks, which can compromise the child's development.

All this calls attention to the importance of incentivizing the creation of family-centered interventions that foster family resilience and strengthen and activate social support networks, creating and supporting associations, groups, etc. as prime strategies in healthcare for children with multiple disabilities. It is essential for both the child and the family to be the target of healthcare and social security teams.

As potential limitations to the study, although we chose databases that are considered robust in the scientific community and with a broad scope in terms of publications in both health and the human and social sciences, the inclusion of more databases might increase the number of original articles and conceptual elements, adding to the material presented in the current meta-analysis. Although we searched the SciELO, no study was found in it that represented the reality in Latin America. Thus, most of the studies in the review were from developed countries in the Northern Hemisphere. We believe that empirical studies are needed that deal with the central issue discussed here, especially with a class and race approach in emerging countries. Another interesting point for investigation is the impacts for the father and mother of the child with multiple disabilities, since the studies analyzed here did not specifically address the issue from a gender perspective.

Contributors

K. O. Dantas conducted the data analysis and interpretation and wrote the article. R. F. Neves participated in the research project's conception, oriented the writing of the article, conducted the critical revision of the content, and approved the final version for publication. K. S. Q. S. Ribeiro participated in the critical revision of the content and approved the final version for publication. G. E. G. Brito participated in the critical revision of the content and approved the final version for publication. M. C. Batista contributed to the critical revision of the content.

Additional informations

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Resumo

A deficiência múltipla em crianças, presente em diversas síndromes, é uma condição que acarreta problemas de ordem física, econômica e social e afeta os pais dessas crianças e suas famílias. O anseio de conhecer melhor essa problemática, sob a perspectiva da análise qualitativa, deu origem ao objetivo deste estudo, que é de identificar e sintetizar o que a literatura científica aborda sobre as repercussões do nascimento e do cuidado de um filho com deficiência múltipla na família. Trata-se de uma metassíntese qualitativa, realizada nas bases de dados Scopus, PsycInfo e SciELO, utilizando-se os descritores: qualitativo; crianças com deficiência; relações pais-filhos; relações familiares; e cuidadores. Os dados foram analisados em três etapas, segundo o método adotado por Noblit & Hare: extração de conceitos de primeira ordem; produção de conceitos de segunda ordem; e síntese interpretativa. Depois do processo de busca e elegibilidade, oito estudos foram incluídos; desses, emergiram seis conceitos de segunda ordem: restrição social; desgaste nas relações familiares; sentimentos que afligem; instabilidade financeira; mudança na dinâmica familiar; e estresse na saúde e no bem-estar. Com base nesses conceitos, elaboraram-se três sínteses: deficiência e parentalidade ideal; o ônus do cuidado; e (re)ssignificações e adaptações da família. Os estudos apontaram que os pais e a família passam por dificuldades advindas das representações sobre a deficiência múltipla e dos encargos do cuidado (problemas de saúde, limitação para outras atividades, aumento dos custos financeiros, mudança de rotina). Indicam, também, que esses elementos penetram e podem interferir nas relações familiares e sociais.

Análise Qualitativa; Crianças com Deficiência; Relações Pais-Filho; Relações Familiares; Cuidadores

Resumen

La discapacidad múltiple en niños, presente en diversos síndromes, es una condición que acarrea problemas de orden físico, económico y social que afectan a los padres de esos niños y sus familias. Con el fin de conocer mejor esta problemática, desde la perspectiva del análisis cualitativo, se decidió realizar este estudio, que identifica y sintetiza lo que la literatura científica aborda acerca de las repercusiones del nacimiento y del cuidado de un hijo con discapacidad múltiple en la familia. Se trata de una metasíntesis cualitativa, realizada en las bases de datos Scopus, PsycInfo y SciELO, utilizando los descriptores: cualitativo; niños con discapacidad; relaciones padres-hijos; relaciones familiares; y cuidadores. Los datos se analizaron en tres etapas, según el método adoptado por Noblit & Hare: extracción de conceptos de primer orden; producción de conceptos de segundo orden; y síntesis interpretativa. Después del proceso de búsqueda y elegibilidad, se incluyeron ocho estudios, de estos, surgieron seis conceptos de segundo orden: restricción social; desgaste en las relaciones familiares; sentimientos que afligen; inestabilidad financiera; cambio en la dinámica familiar; y estrés en la salud y bienestar. En base a estos conceptos, se elaboraron tres síntesis: discapacidad y parentalidad ideal; el coste del cuidado; y (re)significaciones y adaptaciones de la familia. Los estudios señalaron que los padres y la familia pasan por dificultades procedentes de las representaciones sobre la discapacidad múltiple y de la responsabilidad del cuidado (problemas de salud, limitación para otras actividades, aumento de los costes financieros, cambio de rutina). Muestran, también, que estos elementos irrumpen y pueden interferir en las relaciones familiares y sociales.

Análisis Cualitativo; Niños con Discapacidad; Relaciones Padres-Hijo; Relaciones Familiares; Cuidadores

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